

The Lived Experiences of Patients on Hemodialysis: A Metha-Synthesis

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ABSTRACT

Background: Treating chronic kidney disease is connected with receiving long-term dialysis therapy by patients. Hemodialysis remains to be the most common means of therapy for these group of patients worldwide. Although it is life prolonging, the complex nature of treatment procedure affects the patients' normal life and leads to significant symptom burden. Therefore, the purpose of this review is to synthesize recent qualitative studies on the lived experience of patients with hemodialysis.

Methods: A synthesis was done by conducting a search on google scholar and PubMed data bases, reference lists were searched for primary articles and additional hand search on google was also done. Studies that satisfy the Joanna Briggs Institute (JBI) critical appraisal tools and published in English from January 1st, 2011 to September 1st, 2018 were reviewed.

Results: Eight studies comprising of 94 participants were included in this synthesis. Three themes were emerged: Facing countless restrictions in life, having diverse outlooks towards hemodialysis machine and seeking education and competent care from health professionals. The first theme describes the physical limitations, social restrictions, financial restrictions, emotional distress, functional disturbances, and fluid and dietary restrictions that the participant experienced. The second theme, diverse outlooks towards hemodialysis machine, explains about participants positive and non-positive feelings towards the machine. The final theme, seeking education and competent care from health professionals, the need of education and experienced care participants required from health care professionals.

Conclusion: This review come up with that hemodialysis patients have physical, social, psychological, financial and nutritional restrictions; a need of education and some positive feeling towards the dialysis machine. Identification of the key elements of the patient perspective can facilitate provision of high quality health care services that effectively meet the needs of patients on hemodialysis.

BACKGROUND

Chronic Kidney Disease (CKD) is a worldwide public health problem [1-3]. A global estimation shows that more than 500 million people have the disease [4] even though there is little published data from most African countries [5]. End-Stage Renal Disease (ESRD), the final stage of chronic kidney disease [6], is an important public health problem resulting huge morbidity and mortality worldwide [7-10]. The incidence and prevalence of the disease is continues to increase globally [8,11,12].

Patients with CKD need Renal Replacement Therapy (RRT) including hemodialysis, peritoneal dialysis, or transplantation for sustaining and prolonging their life [13,14]. Hemodialysis is remains to be the most common means of therapy worldwide [15], utilized by at least 80 % of patients in over 70 % of reporting countries [16]. Although hemodialysis is life prolonging, the complex nature of treatment procedure affects the patients' normal life and leads to have significant symptom burden [17,18]. Some frequently experienced symptoms includes sleep disorders, peripheral neuropathy, infection, fatigue, stress, anxiety and depression, cognitive changes, pain and sexual dysfunction [19,20]. Additionally, it has impact on patients' body image as a result of grafts or fistula for the dialysis access and has huge financial crisis due to the high cost of dialysis treatment. It also endangered relationships and independency [13]. Generally, their symptom burden has been described as similar to that of patients with advanced cancer [21]. To improve quality of care and properly handle these physical, psychological, emotional, and spiritual changes, nephrology nurses and other health professionals working in nephrology unit need to understand the lived experiences of hemodialysis patients [22]. There are a number of quantitative studies assessed hemodialysis patients' quality of life, coping and adaptation [23-25] and other qualitative studies have attempted to understand the lived experience of patients living on dialysis [13,16,26]. Furthermore, a metha synthesis was conducted on examining the lived experience of hemodialysis patients [27]. This review revealed hemodialysis patient face difficulties in physical and psychological aspects of their life that nurses should understand. The purpose of the current synthesis is to explore the lived experience of patients on hemodialysis treatments from their own perceptions so as to provide updates on the previous study and to ripen a widespread understanding of the impact that hemodialysis therapy has on patients' lives.

OBJECTIVE

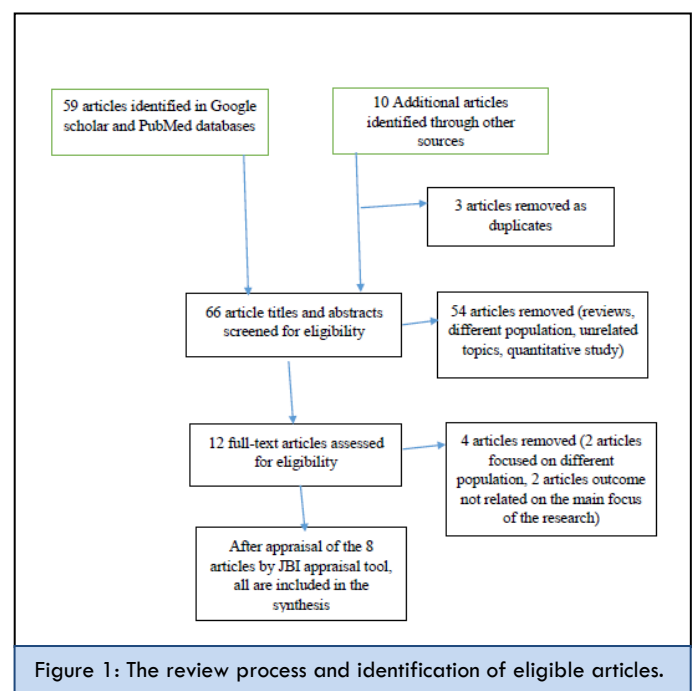
The objective of this review is to synthesize recent qualitative studies of the lived experiences of patients on hemodialysis.

METHODS

Search strategy

An electronic search was conducted on Google scholar and PubMed databases using key words that included "lived

experience", experience, "chronic kidney disease", "chronic renal disease", "chronic renal failure", "renal failure", "end stage renal disease", "end stage renal failure", "end stage kidney disease", CKD, ESRD and hemodialysis. Boolean operators "AND" and "OR" were used to combine search terms. The reference lists of included articles were also reviewed for eligible studies. Additional hand search on advanced google was also done. The search produced 69 articles, 59 studies identified by electronic database and 10 articles identified from other searches. After removal of 3 duplicated articles, titles and abstracts were screened for eligibility for full-text retrieval which resulted exclusion of a large number of (54) articles. Among studies selected for full-text appraisal, 4 studies were excluded. Two studies assessed experience of the provided nursing care which is not the main focus of this review. The other two studies; one focused on the emotional experience of patients with diabetes who are receiving dialysis on treatment adherence and the remaining one study focused on patients on peritoneal & home dialysis. The identification and screening process is illustrated in Figure 1.



Selection criteria

Inclusion criteria: Primary studies explored the lived experiences of adults, ages >18 year-old

Studies published in English language

Studies published between January 1st, 2011 and September 1st, 2018

Both published and unpublished studies

Qualitative studies

Exclusion criteria: Studies conducted on home based hemodialysis

Quality appraisal: The remaining 8 articles were evaluated using Joanna Briggs Institute (JBI) critical appraisal tools for qualitative studies [28] by three independent reviewers (MH,

OY& SM). Dis-agreement were solved by discussion of all reviewers. Of those, four studies satisfied all ten items in the checklist, three studies satisfied nine items and one study fulfilled only eight items. Since all studies reported an adequate (at least 50%) congruity between research methodology, research question, data collection methods, data analysis and interpretation of results, all studies were included in the synthesis (Table 1).

Table 1: Results of critical appraisal by JBI critical appraisal checklist for qualitative studies.

Items	Study							
	Lai et al.	Cooper	Chiaranai	Al-Ghabeesh & Suleiman	Rohini. T & Punitha. V. Ezhilarasu	Valsaraj et al.	Theofilou et al.	Lena Axelsson
Is there congruity between the stated philosophical perspective and the research methodology?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Is there congruity between the research methodology and the research question or objectives?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Is there congruity between the research methodology and the methods used to collect data?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Is there congruity between the research methodology and the representation and analysis of data?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Is there congruity between the research methodology and the interpretation of results?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Is there a statement locating the researcher culturally or theoretically?	No	Yes	Yes	Yes	No	No	Yes	Yes
Is the influence of the researcher on the research, and vice- versa, addressed?	Unclear	Yes	Yes	Yes	Yes	Yes	Unclear	Yes
Are participants, and their voices, adequately represented?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Table 2: Summary of study characteristics on lived experiences of patients on hemodialysis.

Authors & year	Objective & research design	Sample	Data collection & analysis	Findings (categories & themes)
Lai et al. [31]	Objective: to identify the main concerns and needs encountered by incident patients via the exploration of their lived experiences during the early months on hemodialysis Design: qualitative	13 participants	Data collection: Semi-structured interviews Data analysis: interpretative phenomenological analysis	<ul style="list-style-type: none"> Emotional distress: self-perception as a burden to caregivers, loss of purpose in life, threat of death, suicidal thoughts, shock, rejection of ESRD diagnosis and need for hemodialysis Treatment-related concerns: negative symptoms, intrusiveness, access-site related concerns and future treatment Social support: informational & instrumental support
Cooper [32]	Objective: to examine the perceptions and lived experiences of a sample of African Americans who are currently receiving in center hemodialysis Design: phenomenology	10 participants	Data collection: face-to-face & telephone interviews Data analysis: data organization, coding, categorization, and creating theme	<ul style="list-style-type: none"> lifestyle changes: life prior to hemodialysis and perceived threat/susceptibility Lack of education: lack of awareness in communities, modality choice and dialysis experience
Chiaranai [29]	Objective: to better understand the daily life experiences of Thai patients with ESRD who are on hemodialysis Design: Descriptive phenomenology	26 participants	Data collection: Semi-structured interviews Data analysis: thematic analysis	<ul style="list-style-type: none"> Facing life's limitations: a decrease in physical activity, a narrowed social life, dealing with emotional change such as anger, guilt, depression, and unhappiness, spend hidden cost related to hemodialysis treatment Living with uncertainty: Fear of death, do not know future, being scared Feeling insecure that hemodialysis treatment will not last for long Dependence on medical technology: hemodialysis treatment is too important to ignore, feeling save while undergoing hemodialysis treatment, hemodialysis unit is the familiar place, strictly adhere to hemodialysis treatment and cannot live without HD machine
Al-Ghabeesh & Suleiman, [26]	Objectives: describes the lived experience of patients with end stage renal disease on hemodialysis treatment Design: Descriptive phenomenology	10 participants	Data collection: in-depth semi-structured interviews Data analysis: thematic analysis with Colaizzi's methodological interpretation	<ul style="list-style-type: none"> ESRD and HD stressors: physiological, psychosocial, financial, nutritional & cognitive stressors HD between goodness and badness Still alive Quality of care
Rohini. T & Punitha. V. Ezhilarasu [16]	Objective: explore the lived experience of QOL among patients undergoing Hemodialysis Design: interpretive hermeneutic phenomenology based on Van Manen's method	7 participants	Data collection: semi-structured interview Data analysis: thematic analysis followed the six steps delineated by Max Van Manen	<ul style="list-style-type: none"> Crestfallen life: hard pressed life, abounding losses and deserted life Support and comfort Accompanying death Unfulfilled wishes
Valsaraj et al. [30]	Objective: exploring the lived experience of persons undergoing hemodialysis Design: phenomenology	10 participants	Data collection: interview Data analysis: Husserl's method of analysis (bracketing, intuiting, analyzing & describing)	<ul style="list-style-type: none"> Mental agony: Struggle to accept the illness and guilt for causing or worsening the kidney disease due to ignorance or wrong beliefs Physical limitations: variety of symptoms, actual restriction to the overall activity pattern and life centered on dialysis Coping: difficult to adapt with dietary and fluid restrictions Financial burden: taxing treatment expenses and cannot work for a paying job Lack of support: Perceived poor social support and unhappy with the services offered by Government Feelings towards the machine and dialysis: mixed feelings towards dialysis, dependency towards dialysis machine and competency of staff Search for hope and betterment: curious on medical advances, search for treatment alternatives, wish to reduce the dialysis dose and hope for decreased dependency Spiritual coping: acceptance, a spiritual and philosophical process Marital relationship and sexuality: demand lot of marital and family adjustments and diminished sexual interest Uncertainty and fear of tomorrow: loss of hope that 'nothing can improve the condition, uncertain future, fear of fistula failure and fear about dependency
Theofilou et al. [13]	Objective: investigate the lived experiences of hemodialysis patients in Greece Design: descriptive phenomenology	10 participants	Data collection: interview Data analysis: phenomenological procedures	<ul style="list-style-type: none"> Unemployment functional disturbance, non-adherence to medication and diet schedule, social isolation, fatigue, psychological distress sexual dysfunction
Lena Axelsson [21]	Objective: To describe inner thoughts and feelings relating to death and dying when living with hemodialysis	8 participants	Data collection: serial qualitative interview Data analysis: Qualitative content	<ul style="list-style-type: none"> Being aware that death may be near: being reminded of death and dying by the deteriorating body, reminded also by the worsening conditions or deaths of fellow patients and knowing hemodialysis

	approaching end of life Design: phenomenology		analysis	<ul style="list-style-type: none"> as a border to death Adapting to approaching death: looking upon death as natural, preparing to face death, hopes for a quick death and repressing thoughts of death and dying Being alone with existential thoughts: wish to avoid burdening family, lack of open communication with healthcare professionals, hemodialysis withdrawal and hypothetical option
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Data extraction

The data from all of the eligible articles were extracted independently by three reviewers using a pre-piloted data extraction format prepared in a Microsoft Excel spreadsheet. The extracted data included the following information: Authors, year of publication, objective, study design, sample, data collection, analysis method and main findings. Summary of the study characteristics included in the synthesis are presented in Table 2.

RESULTS

The 8 studies included in the synthesis were involved 94 participants. The number of participants enrolled in these studies ranged from 7 [16] to 26 [29]. Seven different countries were represented in the included studies including India (had two studies), Sweden, Greece, Singapore, Jordan, Thailand & United states of America. The synthesis resulted in three themes: Facing countless restrictions in life, diverse outlooks towards hemodialysis machine and seeking education and competent care from health professionals.

Facing countless restrictions in life

This feeling is echoed in all of the eight studies included in this synthesis as having physical limitations, social restrictions, financial restrictions, emotional distress, functional disturbances, and fluid and dietary restrictions. There is an actual restriction to the overall activity pattern of the individuals that made the patient's life miserable.

Hemodialysis has a major impact on the daily life of ESRD patients. Certain symptoms such as fatigue, itching, and cramps are very common in this group of patients and numerous patients with ESRD experience impaired physical, mental, and social functioning [13]. All eight studies talk about physical limitations and functional disturbances and they reported physical symptoms in different ways including decreased energy, drains energy, tiredness, fatigue, chest pain, joint pain, functional disturbances, swelling. One patient said "...when I

go to dialysis, I feel with chest pain and dyspnea, my legs did not tolerate me, and I fallen down several times..." [26].

The physical limitations caused by the disease and its treatment created role dysfunction, resulting in emotional distress [29]. Sexual dysfunction is one of the main role dysfunction causing emotional distress mentioned by hemodialysis patients in three of the studies [13,29,30]. Valsaraj et al. (2014) used the theme "marital relationship and sexuality" to express diminished sexual interest after the onset of illness as well as demand of marital and family adjustments. One participant crying during the interview, said, "My husband is frustrated that I cannot give sexual pleasure to him. I know he has someone else (sob). It is my fault. I cannot be a good wife" [29]. On the other hand, the literatures revealed that hemodialysis patients experienced emotional distress in relation to fear and threat of death, depression, guilty feeling, loneliness, having unpredictable future, suicidal thoughts, shock, rejection of ESRD diagnosis and need for hemodialysis [16,21,26,29-31]. These problems not only affect the patient emotions but also hugely disturbing normal social activities. A restricted social life is highly linked to unhappy life. It was described as being alone with existential thoughts, having lack of support from the family, being unable to fulfill normal social activities. Social restriction in terms of limitations of work, travel as well as social life is also stated in these studies. A participant said "...some people get angry because I did not go to visit them when his son got married and became sad if I refused to drink fizzy drink, they did not understand that this may kill me if I do that .Still people need time to understand what it means to have chronic renal failure" [26].

Hemodialysis patients also maintain their health by doing some restrictions on fluid and food consumptions. Dietary and fluid adherence is of crucial importance to the quality of life and survival of hemodialysis patients [13]. In line with this, fluid and diet restrictions were reported in six studies [13,16,26,29,30,32] as the most stressful restrictions that

adversely affects their quality of life and created social limitations. Rhoni et al. (2016) brought a theme “Unfulfilled wishes” and described as a yearning wishes that hemodialysis patients unfulfilled due to their disease and treatment. A participant stated “In any other illness, people are asked to drink more water, except in kidney failure!” “The worst part about this illness is that you can't drink water as much as you want, how can anyone control thirst... it is an innate feeling that for every human being and animals will have!” [30].

Concerns about changes in financial status is discussed in five studies [13,16,26,29,30]. As a result of ESRD and its treatment, patients suffered financial crisis. The dialysis cost and other expenses of travel, food and children's education are unmanageable because many of them cannot work for a paying job. The sub theme “abounding loss” [16] voices loss ranging of physical strength to loss of job and prosperity. The restrictions experienced by patients with hemodialysis are mostly driven by the physical limitation. It remains as a major obstacle to social, role, and emotional functions as well as it has an incredible impact on the economic hardship created in dialysis patients. Patients realized how the helpless situation of financial drain made them to feel that they are enduring a constrained life. One said “When life was getting settled in a good way, I started to suffer this disease. With that, life started to shatter. I ended up with a great financial crisis. Now it ‘self, within 6 years, I have spent nearly 10 to 11 lakh rupees for this disease” [16].

Diverse outlook towards the hemodialysis machine

Based on this review, the second theme identified is a diverse outlook towards hemodialysis machine. Of the eight reviewed articles, five reported participants view related to hemodialysis treatment and in all of these articles mixed feeling was expressed about the machine. On one hand, participants showed positive feeling for hemodialysis, accepted and appreciated the advanced technology helped to prolong their lives [26,29,30]. The dialysis machine is indispensable for patients with renal failure and play a unique role as one treatment modality. Participants loved the machine and believed that it equals life and patients might have already died without the machine. They also stated that their bodies had coordinated with the machine. A participant said “Doing this (hemodialysis) is like changing the oil in a car. My body is

filled with the nasty sticky oil and it needs to be washed out. I love this machine. It is my lifeline. When I enter this unit and see this machine, I automatically feel better...Because I know that as soon as I connect to it, I will be okay” [29].

On the other hand, the machine was viewed as an intrusive for the patients preferred life style [31,32]. The time-intensive schedule and the strict adherence expected from the patient to hemodialysis treatment deprived patients from occasions to enjoy life. Patients have to go to hospital three times per week and stayed for long hours to have hemodialysis therapy which make them to feel tied to a machine. One said “It is horrible to be tied to a machine for five long hours... time just stay still... nothing can be done, can't move or sleep... why can't they reduce the time to three or four hours?” [30]. Some patients also feel hemodialysis as the cause of several symptoms like apathy, tiredness, cramps, hypotension, and drowsiness, fatigue, and vertigo. These problems occurred due to the ongoing nature of the dialysis therapy and its often-unpredictable complications which made survival very difficult. A participant stated “...I go home apathy and very tired after the hemodialysis session. And only I need to sleep in my bed until the second day. ...this dialysis made cramps, hypotension and drowsiness” [26]. However, effective management of ESRD depends on the individual's devotion with a complex, critically important therapeutic regimen [33] and patients having positive outlook will have better quality of life.

Seeking education & competent care from health professionals

The final synthesized theme was seeking education and competent care from health professionals. In five of the studies hemodialysis patient reflected on the need of education, care and support from health care providers [26,29-32]. They seek information regarding the disease and the hemodialysis machine including medical advances in the direction of kidney replacement. Even though patients agreed that the health professional's helped them during the hemodialysis session; they teach them, and provide them with psychological support, they still have concerns on the need of education and competent care to cope with the disease and the manner of treatment. A patient noted “Need more education out there. They always talking ‘bout cancer and all this other stuff, but nobody really talks about dialysis. They'll brush over diabetes,

but they just never give you the complications of it" [32]. Participants indicated how important it was to be welcomed, communicated and obtained appropriate care from healthcare professionals. The feeling of trust developed as the patient realized that the necessary care & support were given by the professionals. One said "doctors, nurses, and staff here are good to me. This place is my second home. Being here, I can sleep without worrying about anything because I know they will take good care of me" [29]. They believed that the experience and competency of the staff matters even some admired certain staff skills in inserting needle comparing to others.

DISCUSSIONS

The findings of qualitative studies of lived experiences of patients on hemodialysis was analyzed and synthesized in this review and three themes were emerged: Facing countless restrictions in life, diverse outlook towards the hemodialysis machine, and seeking education & competent care from health professionals. The theme facing countless restrictions in life describes the interrelated restriction resulted from the physical symptoms (such as tiredness, fatigue, chest pain, joint pain, functional disturbances, swelling), reduced social function, financial crisis or limitations in the manner of eating and drinking caused by the illness and the ongoing hemodialysis treatment. Physical limitations impose role dysfunction and reduced social activity which in turn resulted in emotional distress. It was apparent that a patient who have shortage of budget for dialysis treatment and restricted fluid and diet show symptoms of thirst, fatigue and depression. Financial limitation is highly related to emotional distress resulting a disrupted social life. Having physical limitations doesn't only bring a reduction in physical activity but also greatly impacts the emotional and social life of the patient. The presence of these all limitations brings countless restriction in life of hemodialysis patient. This largely affects the level of quality of life as perceived by the patient and patients perceived the illness as troublesome which reduce their quality of life. A study shown that the life changes that hemodialysis patient encountered were related to the influence of dialysis on the continuation of work or studies and change on life plans. It stated also that hemodialysis resulted in significant limitations in drinking and eating, travel, sleep, sexual function [34].

Participants mixed view about the machine was evident from this synthesis. Even though participants loved the machine and believed that it equals life they experienced most changes in their everyday lives including the many hours that the dialysis required, ongoing nature of the treatment and dialysis as a cause of several symptoms. Hemodialysis patients had frequently experienced the many complications of hemodialysis. The need for hemodialysis, on the one hand, and the high-risk nature of this potentially harmful treatment, on the other [35].

This synthesis revealed a need of education, competent care and highlights gaps with sharing the necessary information from the side of health professionals. Patients receiving chronic dialysis should receive holistic care considering the physical, psychological and social aspects, which can consequently prolong life and reduce their mortality [34]. Furthermore, the outcome of individual's adaptation is affected by the information/education they received on how to cope with the situation. Thus, it is up to the health professionals to be attentive to contribute positively in the provision of health education, care and support for the patients to facilitate their acceptance [36]. The patients preferred their hemodialysis care to be performed by expert providers and nurses require knowledge, skills, experience and accountability to provide proper hemodialysis care. At the same time, health care systems have also come to focus on the provision of effective evidence-based care building on the patients' expectations [35].

CONCLUSION

This review has been conducted to synthesize the recent evidence about the lived experience of patients undergoing hemodialysis therapy. It revealed physical, social, psychological, financial and nutritional restrictions; a need of education and some positive feeling towards the dialysis machine as perceived by hemodialysis patients. Identification of the key elements of the patient perspective can facilitate provision of high quality health care services that effectively meet the needs of patients on hemodialysis. Moreover, health professionals should provide adequate education regarding CKD and hemodialysis therapy for their patients that may enable them to have a better health outcome.

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AUTHORS' CONTRIBUTIONS

MHG performed literature search, reviewed literature, made the analysis and wrote the initial drafting of the manuscript. OY & SM made review of literature, participated in the analysis and revision of the manuscript. All authors read and approved the final manuscript.

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